
Special Report

AHCPR Focuses on Information for Health Care Decision Makers

John M. Eisenberg

In the spring of 1989, the annual report of the Physician Payment Review Commission (PPRC) called for an additional federal investment in research “to determine the medical outcomes and costs of clinical alternatives and their effect on medical outcomes and the delivery of care.” The PPRC report went further, formally recommending that “the Federal government should support effectiveness research and practice guidelines through increased funding, coordination, and evaluation” (PPRC 1989).

Later that year, Congress passed the Omnibus Budget Reconciliation Act of 1989 (OBRA 89), which established the Resource-Based Relative Value Scale (RBRVS) for payment of physicians under Medicare, and included a provision establishing the Agency for Health Care Policy and Research (AHCPR) “for the purpose of enhancing the quality, appropriateness, and effectiveness of health care services and access to care” (PL 101-239). Lawmakers recognized that, if the playing field of fee-for-service physician payment were to be leveled and facilitate decision making based on patients’ likely benefit, then better information would be needed to support those decisions. AHCPR was created on the foundation of the National Center for Health Services Research, which supported much of the early research leading to the development of federal policy initiatives in health care delivery—including the RBRVS, Diagnosis-Related Groups, and the Experimental Medical Care Review Organizations (EMCROs), which served as a predecessor to federally sponsored quality review programs.

Recent changes in American health care have provided further impetus for AHCPR’s mission. In addition to meeting the continued need for information that will inform decisions by clinicians and their patients and decisions

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by public policymakers, the Agency's current priorities must also address the critical need for the information that makes a market-based health care system run effectively and efficiently. The Agency's premise is that decision makers at all levels—clinicians and patients, health system leaders, and federal, state, and local policymakers—will make decisions using science-based, objective information if that information is available.

Based on these principles, AHCPR's priorities are:

- To conduct and support research on the outcomes and effectiveness of health care;
- To ensure that clinicians, patients, health care system leaders, and policymakers have the information that will enhance quality of care; and
- To identify gaps in access to and use of health care services, achieving value for the Nation's health care dollar, and helping the market and policymakers find ways to address those gaps.

SURVIVING A "NEAR DEATH" EXPERIENCE

AHCPR has been working to recover from a "near death" experience that occurred when its funding was reduced from \$159 million in Fiscal Year 1995 to \$125 million for FY 1996. This drastic reduction—spurred partly by congressional concerns about the impact of AHCPR's research—fueled the Agency's effort to consult with its stakeholders about the type and scope of the research and activities it would support and conduct. The Agency's new priorities are one outcome of that ongoing evaluation.

President Clinton requested \$171 million for AHCPR in FY 1999. (In FY 1997, the Agency's budget was \$143 million, and it was \$146 million in FY 1998.) Equally important, the President affirmed the role of AHCPR—and health services research—by including it in a new federal research trust fund, the Research Fund for America. As Secretary Shalala described the fund in 1998 in her presentation of the 1999 budget, "The President and the Vice President announced the Research Fund for America, to launch a new era of path-breaking scientific inquiry . . . with new resources for our constellation of stellar research agencies—including the National Institutes of Health, the Centers for Disease Control, and the Agency for Health Care Policy and Research." The Fund would provide AHCPR with financial support, in the words of Secretary Shalala, "to speed medical findings from the lab to the

clinic—part of [the Department of Health and Human Services'] stronger effort to improve health care quality.”

Although the outcome of the FY 1999 budget process was still several months away when this article was drafted, AHCPR was in the process of planning the types of research it will fund in FY 1999. The goal is to balance research conducted by researchers in the Agency and that conducted by outside investigators who submit applications either in response to a targeted proposal or to the Agency's General Program Announcement.

AHCPR published a General Program Announcement this spring, encouraging submission of research applications in three major areas that coincide with the Agency's three priorities: projects that identify areas for improvement in health outcomes; research that strengthens quality measurement and improvement; and projects that identify strategies to improve access, foster appropriate use, and reduce unnecessary expenditures. Researchers are encouraged to emphasize the needs of priority populations, including minority populations, women, and children (*NIH Guide* 26 March 1998).

STREAMLINING AND FOCUSING GRANTS AND THE AGENCY

As part of the Agency's reemphasized focus on the needs of its customers, who include health services researchers, it has accelerated the cycle of research from application to publication. The first step in this process is an ongoing review of AHCPR's grant application procedures to make the process less burdensome and to improve the Agency's response time. AHCPR already has streamlined summary statements; limited to two the number of times an applicant may resubmit an application; invited concept letters as an adjunct to technical assistance; expedited the deferral process; and provided advance approval for applications to request direct costs of more than \$500,000. In addition, AHCPR has restructured its study sections so that the substantive expertise of members is more focused. At the same time, the Agency has created a “reviewer reserve” on which it can call for additional expertise.

The streamlined grant application process is one example of AHCPR's efforts to improve the translation of investigators' ideas into new information for health care decision makers. AHCPR also is expanding its use of small grants and conference grants as well as encouraging quick peer-reviewed publication of the research it sponsors. It is promoting projects with shorter

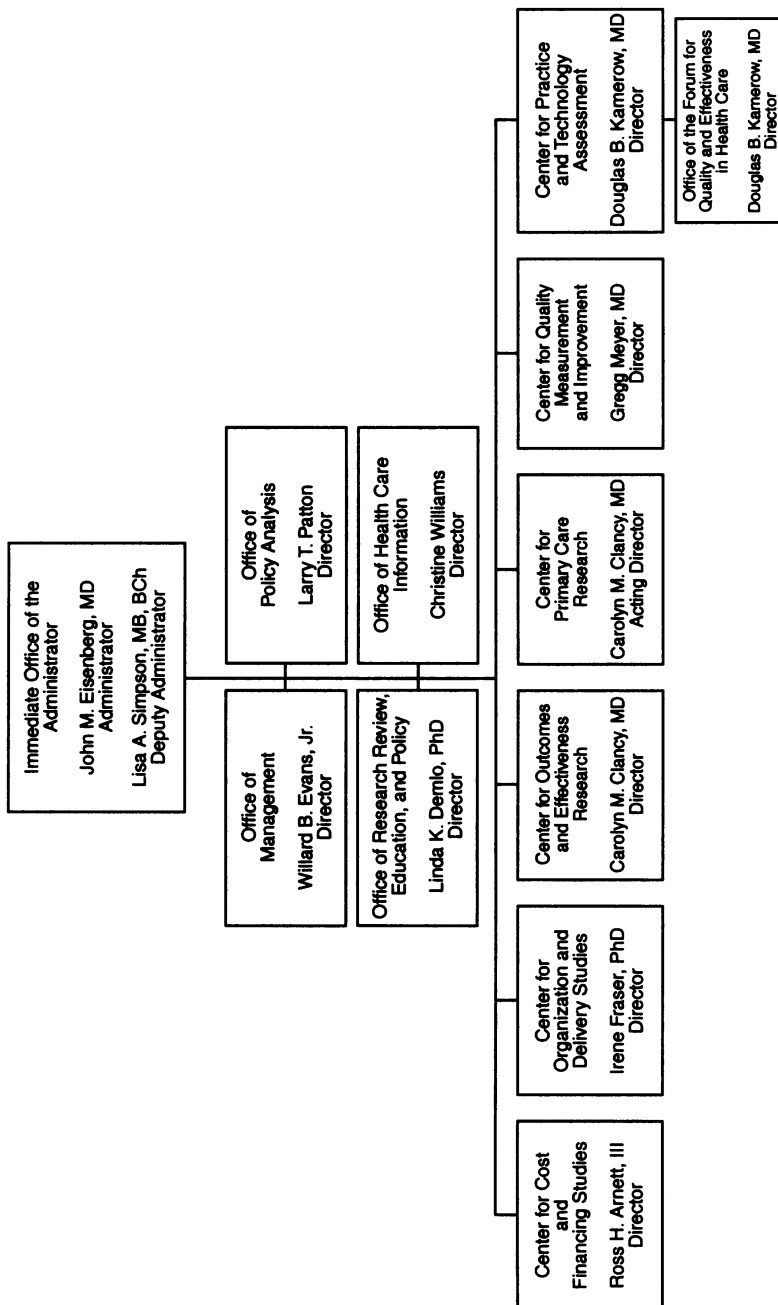
time lines. The Agency also encourages researchers to seek partnerships in order to answer important questions in new areas of health care delivery, including identifying areas of research where decision makers need information, opportunities for data and for the evaluation of innovations that are being developed, and collaboration to translate and implement the findings of funded research. For example, 11 AHCPR-supported researchers last fall published a series of articles in *Health Affairs* that explored different aspects of the impact of market forces on the delivery of health care services. The studies were the products of a conference that AHCPR held to set a research agenda, and were published in less than two years from the time the grants were awarded (*Health Affairs* 1997).

AHCPR also has reviewed its internal structure to find ways to improve its operations and to integrate its new priorities and direction. Among those priorities is promotion of the use of evidence-based medicine in the health care system. To that end, AHCPR has concentrated much of its work on evidence-based medicine into a single entity, the Center for Practice and Technology Assessment (CPTA). This new Center houses the former Office of the Forum for Quality and Effectiveness in Health Care, and will include the functions of the previous Center for Health Care Technology.

CPTA focuses on closing the gap between what is known and what is done, to help improve the quality of health care. Its major activities include producing evidence reports and technology assessments, principally through AHCPR's 12 Evidence-based Practice Centers; facilitating the development and operation of an Internet-based National Guideline Clearinghouse; leading the improvement of clinical preventive services, especially by sponsoring the Third U.S. Preventive Services Task Force. CPTA also will conduct and support research on the implementation of evidence-based recommendations into the health care delivery system and on methodologic aspects of this work.

AHCPR also is integrating its efforts in informatics throughout the Agency, because the use of information technologies is a central component of both conducting health care research and improving the quality of health care services. Informatics has greatly enhanced the collection and analysis of health care data, and has created a revolution in the ways information is used by the key decision makers in health care—patients and clinicians, health system leaders, and policymakers. Seamless information systems, such as those that link administrative, financial, and clinical data, have a profound potential to enhance the provision of quality health care services, but there has been far less implementation than hoped for and less evaluation of their impact than needed.

U.S. Department of Health and Human Services AGENCY FOR HEALTH CARE POLICY AND RESEARCH



STUDYING CLINICAL AND ORGANIZATIONAL OUTCOMES

One of the goals of Congress in 1989 was to create a federal agency that would study the outcomes of clinical care services, translate and disseminate that information to improve health care quality, and provide a scientific basis for any federal payment of medical services.

Although AHCPR was well known for its guideline program, the development and dissemination of guidelines was part of a broader agenda in health care outcomes. For the past two years, the Agency has refocused on the scientific basis for outcomes and on improving their use in improving care. Thus, the Agency no longer supports the guideline development program, instead both supporting outcomes research that provides information about effectiveness in medical care and supporting ways of using this information to enhance decision making at all levels.

Since 1989, AHCPR's clinical outcomes research initiatives, including its 22 Patient Outcomes Research Teams (PORTs), pharmaceutical outcomes projects, and medical effectiveness research have helped build the science base underlying day-to-day clinical practice.

For example, AHCPR's Stroke Prevention PORT found that fewer than 25 percent of eligible patients receive appropriate anti-coagulation services and that half of those patients receive an incorrect dose (Matchar et al. 1994). AHCPR, in partnership with Duke University and the Dupont Merck Corporation, is supporting an intervention trial to find the most effective way to administer anticoagulants to this population.

One of the most important priorities of AHCPR is to translate and disseminate the findings of this outcomes research into tools and information that can be used by its customers to improve the quality of the care they provide or to make good health care decisions. AHCPR's Cataract PORT, which was led by investigators at Johns Hopkins University, developed the VF-14, a visual function index that gauges the impact of cataracts on patients' ability to perform 14 activities, including reading and driving. The index also allows for comparisons of patients' visual function before and after removal of a cataract (Steinberg, Tielsch, Schein, et al. 1994).

One of the most important mandates for AHCPR is to continue to evaluate its program of outcomes and effectiveness research to ensure that the research it supports answers several basic questions: Does it work? What does it cost? And Does it provide value? The goal of this "outcomes of outcomes" evaluation is to ensure that the Agency continues to provide critical

information that enhances decision making, improves the quality of health care, and builds the evidence base for medical practice.

To enhance its efforts to build the science base of clinical practice, last year AHCPR named 12 Evidence-based Practice Centers (EPCs). These Centers analyze the available evidence of the effectiveness of selected conditions, interventions, or procedures. The resulting reports can be used by health care organizations, medical societies, physician practices, and others, to develop quality improvement programs.

A hallmark of AHCPR's Evidence-based Practice initiative is that the work of the 12 Centers is the product of an extensive collaboration with the public- and private-sector organizations that plan to implement the findings in their programs. For example, the Health Care Financing Administration (HCFA) has asked AHCPR to evaluate swallowing problems in the elderly. The evidence report on attention deficit/hyperactivity disorder was nominated by the American Academy of Pediatrics and the American Psychiatric Association, who are planning to collaborate on the development of a practice improvement program using the analysis produced by the EPC. The Evidence-based Practice initiative will also provide a research base for the U.S. Preventive Services Task Force with updated, critical assessments of the literature about the effects of preventive services in clinical settings.

AHCPR also is branching into a new area of outcomes research with the support of two Centers for Education and Research in Therapeutics (CERTs), an authority granted under the Food and Drug Administration Modernization and Accountability Act of 1997 (PL 105-115). CERTs are a natural outgrowth of AHCPR's pharmaceutical outcomes research program. Their mission will be to support research to investigate new uses and risks of medical products; provide information to health care participants to help them use new products more effectively; improve the appropriate use of medical products by health professionals; and prevent adverse effects of medical products and the consequences of these effects.

The Agency also is continuing to conduct assessments of new and existing technologies for Medicare and the Department of Defense as mandated by its authorizing legislation. However, AHCPR's evolving technology assessment program, now located in the Center for Practice and Technology, is developing innovative strategies for conducting assessments through the EPCs as well as by intramural staff at AHCPR, and for getting the information to decision makers. AHCPR's assessment of lung volume reduction surgery (LVRS) is a case in point. AHCPR's assessment found insufficient evidence of

the effectiveness of LVRS to treat chronic obstructive pulmonary disease, so it recommended limited reimbursement for the procedure under a clinical trial. An LVRS trial is now being conducted at the National Institutes of Health, with its clinical costs supported by HCFA and its cost-effectiveness analysis supported by AHCPR.

AHCPR's efforts to build the evidence base for better health care include finding innovative formats for promoting the use of evidence in medicine. This innovation includes using new technology and working with partners to translate and disseminate research into practice. For example, AHCPR and its partners, the American Association of Health Plans and the American Medical Association, have developed an Internet-based National Guideline Clearinghouse™ (NGC), which will be a one-stop-shop for clinical practice guidelines when it is released later this year. Each entry entered in the NGC will include a structured abstract that describes how the guideline was developed, a comparison of guidelines on similar topics, either the full text of the guideline or electronic links to the full text, and information on how to obtain the guideline.

An important component of improving health care decision making is to understand how the health care system works and how health care is delivered. It is just as important to examine the outcomes of the organizational and financial changes in health care as it is to study the outcomes of clinical care. The two areas of study are interconnected. Improving the quality of clinical care cannot be successful if the foundation on which those services are provided is untested. Information on clinical care is a necessary but not sufficient condition for improving health care quality. That information must be linked with organizational strategies and incentives for change or the information is not likely to be used effectively.

AHCPR's initiatives on the outcomes of organizational aspects of health care also recognize the changing dynamics of the health care system. It is no longer sufficient simply to compare fee-for-service and managed care; the lines between them have blurred as more managed care plans have incorporated elements of fee-for-service payment and vice versa. Instead, it makes more sense to study the effects of the components of managed care or fee-for-service on the quality of health care. For example, AHCPR, in partnership with the American Association of Health Plans Foundation, is supporting a \$7 million research initiative to determine the effects of different features of health plans on the quality of care provided to patients with chronic illnesses. This program will support six research teams whose grants were announced in June.

QUALITY MEASUREMENT: FOR CHOICE AND IMPROVEMENT

In March, the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry released its final report after a year of deliberations. The report provided several avenues to improve the quality of health care services. Research is the foundation of each of these avenues. The Commission noted that "improving the quality of American health care and enhancing Americans' health requires a commitment to delivering health care based on sound scientific evidence and to the continuous innovating of new, effective health care practices and preventive approaches" (*Quality First: Better Health Care for All Americans* 1998).

As an agency that has distinguished itself by conducting and sponsoring research on the structure, process, and outcomes of care (the three key elements of quality assessment and improvement described by Donabedian), AHCPR has contributed to the Nation's quality of care agenda since its inception. While AHCPR has traditionally supported and conducted research to improve the quality of health care services, the emphasis on providing information for decision making has refocused the Agency's program of quality research. AHCPR's research in quality falls into two categories: quality information for choice and quality information for improvement.

The demand for information on quality has grown dramatically over the last decade as consumers and purchasers increasingly seek to make choices based on value. This desire for information that drives choice can be fed by improved methods of quality measurement, including report cards and measures of satisfaction that allow consumers and purchasers to comparison-shop health plans and providers. For example, AHCPR's Consumer Assessment of Health Plans (CAHPS) is an innovative project that developed and tested series of questionnaires for use by public- and private-sector health plans, employers, and other organizations to survey their members and employees. The results of CAHPS can help consumers and group purchasers compare health plans and make more informed choices based on information about the quality of the services provided.

CAHPS's questionnaires and report formats are being tested widely in demonstration sites around the country (CAHPS Survey and Reporting Kit 1998). Test sites include Ford Motor Company's Department of Health Care Quality, which is using CAHPS to gauge employees' experiences with their health plans in two markets, five large health plans, and more than 20 states. HCFA also has fielded a CAHPS survey, developed in a partnership

between AHCPR and HCFA, to assess the quality of care in Medicare managed care plans, and the Federal Office of Personnel Management will be using CAHPS to help federal employees select health plans based on information about quality beginning in 1999. In addition to providing the first consumer-driven tool to gauge enrollees' experience with their health plans, CAHPS provides an excellent model of one of the ways AHCPR will fund future research: partnership and collaboration. CAHPS was developed by a consortium of grantees at three institutions, RAND, Harvard, and Research Triangle Institute.

In addition to providing information on quality for consumers and purchasers who are deciding which plan to join or to offer, information is important to those who are trying to select the highest-quality health care services. AHCPR will sponsor research on measuring the quality offered by different providers and the quality available from different services.

Information on quality for its improvement, on the other hand, gives health plans and providers benchmarks and gauges to improve the way they provide health care. AHCPR recently released CONQUEST 2.0, an update of a unique computerized compendium of clinical quality measures that can help users select measures that best meet their needs. CONQUEST consists of two interlocking databases that offer a single, comprehensive resource for health plans and purchasers to use in evaluating and comparing more than 1,300 clinical quality measures.

AHCPR's work in the development of clinical measures goes beyond cataloging and evaluating existing measures. New measures must be developed to assess the changing environment of health care. AHCPR's Expansion of Quality Measures project, or Q-Span, is developing new measures that will address certain conditions; population subgroups, particularly vulnerable populations such as the chronically ill; and a full spectrum of treatment settings, such as rehabilitation and home care. Extramural projects funded by AHCPR's Q-Span Program include measures to test and validate individual HEDIS measures; global measures that summarize and weigh disease-specific measures for women over 50 and men over 18; and detailed measures of cardiovascular care by health plans for acute myocardial infarction, congestive heart failure, and hypertension.

AHCPR recently funded eight grants designed to build the scientific foundation for developing new measures and new ways of assessing health care quality. The studies, funded for a total of \$7.6 million over five years, cover a wide range of issues, including the impact of the structure and organization of nursing homes on the quality of care, development of new

measures for assessing the quality of carotid endarterectomy, comparisons of the effectiveness of measures for chronic conditions with general measures of quality, and the development of predictive measures that can be used for patients and clinicians to make decisions about surgery.

STUDIES OF COST/USE/ACCESS

Policy is made at all levels of the health care system, from examining room to boardroom to legislative chamber. AHCPR seeks to provide information about the changes to the health care system and the development of the health care market that will allow these decisions to be made using evidence and a scientific foundation. This agenda includes sponsored research in the social and behavioral sciences, as well as several unique databases that offer information on the cost of, use of, and access to health care in this country. Because the finest health care quality will not improve health if it does not get to people, the importance of research on cost, use, and access is critical to all aspects of the Agency's agenda.

For example, AHCPR's Medical Expenditure Panel Survey (MEPS) is a comprehensive and timely source of detailed information on how Americans use and pay for health care services (Cooper and Schone 1997). MEPS consists of five interrelated components—the Household, Medical Provider, Insurance, Employer, and Nursing Home Surveys—which collect data from a nationally representative sample of 9,400 households representing more than 24,000 individuals. MEPS is unique not only because of its scope, but because it is the only national survey that collects expenditures from the non-Medicare population. Data from MEPS are used by public- and private-sector organizations to develop national and regional estimates of the impact of changes in financing, coverage, and payment policy, and to make estimates of who benefits from and who bears the cost of these changes (Weinick, Weigers, and Cohen 1998). The MEPS has replaced the National Medical Expenditure Survey, which was last conducted by the National Center for Health Services Research in 1987.

The HIV Cost and Services Utilization Study (HCSUS), of which AHCPR is principal sponsor, is a large-scale study that provides policymakers with data on the costs and utilization of different services for persons infected with HIV. HCSUS also collects primary data about access and barriers to care in different geographic locations and health care delivery system settings. HCSUS was funded through a cooperative agreement with RAND for four

years beginning in FY 1994. Currently, AHCPR, RAND, Merck and Co., and Glaxo Wellcome, Inc. are collaborating in the support of a landmark study using HCSUS that examines the use of and costs associated with multi-drug combination therapies, including protease inhibitors, for treatment of human immunodeficiency virus (HIV).

Another AHCPR database, the Healthcare Cost and Utilization Project (HCUP-3), is now going through a period of evolution. The result of a partnership between the federal government and states, HCUP-3 consists of two databases of patient-level information for inpatient hospital stays in a uniform, protected format. The databases are the Nationwide Inpatient Sample (NIS), a national sample of about 900 hospitals, and the State Inpatient Database (SID), which covers inpatient care in community hospitals in 12 states that represent nearly half of all U.S. hospital discharges.

The original objectives of the HCUP-3 project were to develop a large hospital database for research purposes and to develop a uniform format for the data that would be included. HCUP-3 data are used by researchers within and outside of AHCPR. HCUP-3 is now working to improve the timeliness of its data collection and release to keep up with the rate of change within the health care system. Designed primarily as a database of hospital information, we anticipate that HCUP-3 will now collect data from other health care settings.

In addition to these databases that are being collected with AHCPR support, intramural researchers are using existing databases to develop a cost of illness inventory, describing illnesses in clinically relevant ways and enumerating the costs of these health problems.

TRAINING AND NURTURING HEALTH SERVICES RESEARCHERS

An important and growing role for AHCPR is to promote the careers of new and established health services researchers in this country. The Institute of Medicine estimates that the need for qualified health services researchers will soon outstrip supply (IOM 1995).

Through the National Research Service Award (NRSA) program, AHCPR provides funds to institutions for the support of predoctoral and postdoctoral training programs in health services research. NRSA fellowships also are awarded to individuals who have completed their doctoral degrees (including M.D.), and under the Health Services Dissertation Research

program, the Agency provides dissertation grants for doctoral candidates to complete research as part of their doctoral program.

AHCPR also supports the training of health services researchers through the institutional Training Innovation Incentive Award programs. The goal of this new project is to support the development of innovative models for training new investigators to address emerging issues in health care policy and delivery, and to respond to the changing analytical needs of health care providers, health plans, purchasers, and policymakers.

AHCPR also provides opportunities for sabbaticals in a number of areas, including pediatrics, dentistry, nursing, and family medicine. For example, AHCPR, in conjunction with the American Academy of Nursing, supports training for a nurse scholar-in-residence. Under this program, senior nurse scientists help AHCPR develop areas of investigation that integrate clinical nursing questions with critical issues of quality, cost, and access to health care.

IT'S NOT ENOUGH JUST TO PUBLISH

In addition to providing these training opportunities, AHCPR works with the health services research community to improve the translation and dissemination of research. Researchers have a responsibility to work with their funding institution, whether it is AHCPR, another public-sector organization, or a private-sector funder, to translate their research into a format that makes a difference in the health of the public or that improves the quality of health care services. They should be able to explain their research and its potential impact to a non-research audience.

An analysis of outcomes research by AHCPR has led to the conclusion that the majority of work to date has been descriptive, doing a good job of detailing "the problem." A fundamental premise of a market-driven health care system is that information for decision makers is critical, and this presents an enormous challenge to funders and the research community. The challenge is to reframe the question from "How can I educate decision makers about the importance of my work?" to "What information do decision makers need, and how can research produce both timely and relevant information to support decisions?"

AHCPR works with researchers to help them translate their work by getting them involved at all stages in the cycle of research from grant application to publication, and having them work with the users of the research.

CAHPS, the Evidence-based Practice Centers, research efforts to promote value-based purchasing, and expert meetings where research agendas are set are examples of collaborations sponsored by AHCPR that bring researchers and users together. AHCPR's conference grant program supports conferences that bring together researchers, experts, and decision makers to discuss the critical issues facing the health care system.

AHCPR's User Liaison Program (ULP) is another example where researchers and experts work together to provide technical assistance to states and local policymakers on a wide range of issues. For example, a ULP workshop geared toward state policymakers recently examined the latest research findings on the uninsured and what state governments have been doing to solve the problem. Another ULP conference has helped state legislators and executive branch officials implement the states' Children's Health Insurance Program (CHIP) enacted last year by Congress. AHCPR's Website (www.ahcpr.gov) provides information on all of the Agency's programs and the research it supports. Because AHCPR is an arm of the federal government, the products it develops, such as CONQUEST and MEPS data, are in the public domain. They can be downloaded from the AHCPR Website. Researchers and the public can sign onto a list-serve to receive AHCPR's monthly review of research, *Research Activities*, and any press releases and advisories issued by the Agency. The majority of products available on the Website, as well as older AHCPR publications, also are available from AHCPR's Publications Clearinghouse at 1-800/358-9295.

FINAL THOUGHTS

Providing objective, science-based, timely information to health care decision makers—patients and clinicians, health system leaders, and policymakers—is the challenge that faces health services research and AHCPR in the next century. Meeting this challenge depends heavily on the continued collaboration and communication between the Agency and the health services research community. The two must work together to conduct high-quality, relevant research that is translated and disseminated to improve the quality of health care services and, ultimately, the public's health.

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